

status Report

The Quarterly Newsletter on
Disability Issues in Alberta

THE PREMIER'S COUNCIL ON THE STATUS OF PERSONS WITH DISABILITIES

AUGUST 1999

New Minister for Council

As part of the recent Alberta Government Cabinet reorganization, the Premier's Council now falls under the new Ministry of Health and Wellness—and it now reports to the Associate Minister, Gene Zwodzdesky. See page 2 for more details.

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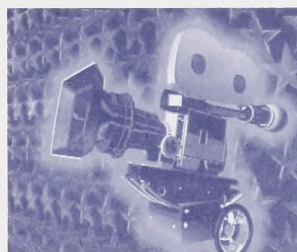
Pictures Into Words

"Described" videos bring movies to visually impaired people

A Canadian organization is opening up the cinema to people who are blind or visually impaired.

It's called described video, and it's produced in Canada by AudioVision Canada, a division of the National Broadcast Reading Service (NBRS). NBRS is a non-profit organization that is best known for VoicePrint, a newspaper reading service that visually impaired people can listen to on cable TV networks across Canada, including Alberta.

In described videos, movies in their original form are augmented with an unobtrusive descriptive sound track that matches perfectly with the action on the screen. "It's like the announcer who adds colour to a hockey broadcast during breaks



in the action," says VoicePrint Calgary Bureau Chief Lynne Rach.

Described videos are VCR-ready and require no special equipment.

The concept for described video was introduced by WGBH, a Boston-based PBS station. AudioVision Canada is attempting to open a Canadian market with professionally produced products available at a more af-

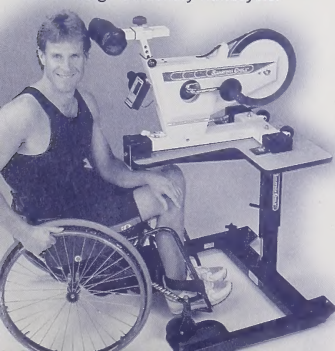
fordable price. To date, close to 40 movies have been described—most of which are classics, such as Agatha Christie's *Witness for the Prosecution*. AudioVision Canada hopes to describe up to 300 additional titles per year.

Rach says the ideal way for the estimated two million visually impaired Canadian consumers to have access to the videos is through libraries. "Described movies on the special needs shelves of libraries would be a rich enhancement to an already valuable service to the needs of the disabled," says Rach.

Cost to libraries is \$18.75 per movie. Proceeds of the service will help offset the costs of operating the VoicePrint service. For more information, contact Lynne Rach at 403/515-8430.

Calgary Accessible Fitness Centre Moves a Step Closer to Reality

The Lifestyle Fitness Centre will provide access to specialized equipment such as the Saratoga Stationary Handcycle.



The Lifestyle Fitness Centre, to be located at Lindsay Park in the centre of Calgary, will be a totally accessible fitness and resource centre for use by people with physical disabilities.

The Lifestyle Fitness Centre has been spearheaded by a small group of volunteers who joined together in hope of setting up a well-equipped workout centre that would provide people with disabilities access to specialized equipment.

A study completed by the Canadian Paraplegic Association (Alberta) showed that there was a severe shortage of accessible fitness facilities in Calgary, and that people with disabilities wanted a

place to exercise. Armed with the study, the volunteers then approached the directors of Lindsay Park about incorporating the Lifestyle Fitness Centre into their world-class facility. The directors agreed, and a partnership was created with the goal of making this project a reality.

The plans call for the Lifestyle Centre to be a place where those with disabilities can use state-of-the-art adapted exercise equipment in a barrier-free setting.

Currently, volunteers are working with Lindsay Park staff to develop a major fundraising drive to make the Lifestyle Centre a reality.

Chair Welcomes New Minister

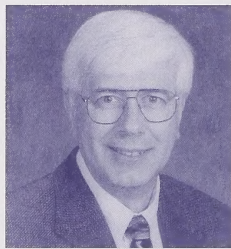
I would like to take the opportunity to publicly issue a warm welcome to Gene Zwozdesky as Minister Responsible for the Premier's Council. I would also like to tell *Status Report* readers why I believe his appointment bodes well for all Albertans with disabilities.

First, the Minister (his official title is Associate Minister of Health and Wellness) has a fine track record in representing the disadvantaged in our society. In 1998, he chaired the Edmonton Task Force on Homelessness).

Second, his appointment means that the Premier's Council mandate of improving the overall status of Albertans with disabilities will now have additional representation at the Cabinet table.

As you know, the Council's former Minister Responsible, Halvar Jonson, has had a number of other priorities to deal with during his tenure—none more pressing than that of ensuring the province's reorganized health care system is able to meet the needs of all Albertans. We sincerely thank Minister Jonson, who continues as Minister of Health and Wellness, for his years of commitment to the Council's cause.

With Associate Minister Zwozdesky's specific assignments of the Premier's Council and the Alberta Alcohol and Drug Abuse Commission



Rob Lougheed, MLA

(AADAC), we believe he will bring additional awareness of disability concerns to his fellow members of the Cabinet.

I have the privilege of remaining Chair of the Premier's Council and

I am looking forward to working in concert with the new Associate Minister and further championing your concerns to my Caucus colleagues. I look forward to hearing your concerns and comments during our community consultation process, scheduled to begin this fall.

*Rob Lougheed, MLA
Clover Bar/Ft. Saskatchewan*

PDD Situation Requires Speedy Resolution

Just as proposed changes to AISH and Assured Support programs finally seem to meet with community approval, another situation has arisen that has created fear and anxiety for Albertans with disabilities served by Persons with Developmental Disabilities (PDD) boards.

Our community contacts have revealed to us that there are two concerns: the transfer of responsibility to a new ministry, and significant projected budget deficits in this fiscal year that could restrict delivery of important services.

With respect to the former, there was great concern by community service providers, consumers and advocates after the recent government restructuring, which saw responsibility for PDD boards being placed with the new department of Health and Wellness. Previously, responsibility was with the now defunct department of Family and Social Services—consumers, families and their advocates were generally very pleased with the type and extent of support they received from there. The problem with Health and Wellness, according to critics of the transfer, is that the new department will remain based on a "medical model" which they describe as "sickness and cure" oriented, relying

on institutional care, and historically associated with controversial procedures such as sterilization and genetic abortions.

With respect to projected budget deficits, some programs and services are already being cut. At the time of writing, Alberta Health and Wellness and the PDD Provincial Board and Community Boards are working to resolve the budget concerns. At press time, Health and Wellness Minister Halvar Jonson had announced \$10 million in additional funding for this fiscal year. The Minister has also asked Associate Minister Gene Zwozdesky to undertake a comprehensive review of the six Community PDD Boards, to be completed by this December.

Whatever the solutions are, it will be critical to find them soon—there's been enough fear and anxiety experienced by extremely vulnerable people who are already marginalized in our world.

We are always concerned when we hear that the rights of—or the supports for—people with disabilities are jeopardized. As per our mandate, we will continue to monitor this situation and, where possible, make informed recommendations to government that are in the best interest of people with developmental disabilities.

Meet the Minister

The Honourable Gene Zwozdesky, newly appointed Associate Minister of Health and Wellness, has a rich and varied background.

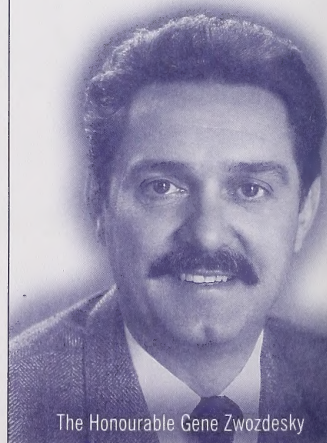
He has bachelor degrees in Arts and Education from the U of A, and has studied Public Administration at the U of A's Faculty of Extension.

First elected to the Legislature in 1993, he has been a teacher and has owned a number of small businesses. He also served as Executive Director of both the Alberta Cultural Heritage Foundation and the Alberta Ukrainian Canadian Centennial Commission, and is a former Music Director of the renowned Shumka Dancers and Cheremosh Dancers.

He has an extensive track record in the community. He is a Co-Creator and Chairman of the Great Canadian Awards, and has been Vice-President and Treasurer of both the Alberta Recording Industry Association and the Edmonton Heritage Festival Association.

He has won numerous awards for community service, including the City of Edmonton Ambassador Award for Business and Tourism, the Province of Alberta Achievement Award for Culture, the Government of Canada Achievement Award for Arts, and the Government of Canada Merit Award for Multiculturalism.

Born on July 24, 1948, Mr. Zwozdesky was raised in the rural Alberta communities of Grand Centre, Hinton, and Sangudo. He has lived in Edmonton for the past 34 years. He and his wife Christine have two children.



The Honourable Gene Zwozdesky

Provinces Have Much in Common

Many of the disability issues we experience in Alberta are experienced in other provinces and territories—and therefore affect most Canadians with disabilities.

Each year, provincial advisory bodies from across Canada meet to share challenges and successes related to disability policy. This year, our Council hosted the meeting, which took place June 19-22. Advisors from British Columbia, Saskatchewan, New Brunswick, Nova Scotia and Northwest Territories attended. Others unable to attend were kept up to speed on discussions via e-mail and conference calls.

Additionally, our meetings were attended by two Members of Parliament: Andy Scott, Chair of the Federal Task Force on Disability Issues that culminated in the report *The Will to Act* (1996), and a member of the Parliamentary Sub-Committee on the Status of Persons with Disabilities; and Dr. Carolyn Bennett, also a champion of disability issues and Chair of the Parliamentary Sub-Committee on the Status of Persons with Disabilities. Karen Junke, Director of the Office for Disability Issues at Human Resources Development Canada, and her provincial counterpart Deborah Welch, also joined us.

The meetings were kicked off with a reception the evening of June 19th. Welcoming comments were provided by both Rob Loughheed, MLA and Chair of the Premier's Council, and Gene Zwozdesky, Associate Minister of Health and Wellness and Minister Responsible for the Premier's Council. Besides delegates, several Council Members and some 30 representatives from community and government organizations were in attendance. The reception provided an opportu-

nity to bring everyone together with no formal agenda—and feedback tells us it was very valuable.

The meetings were long, intensive, lively and packed with information. Our agenda included provincial updates, initiatives at the federal level, and methods of influencing federal disability policy.

Perhaps the most rewarding part of the meetings was having Mr. Scott, Dr. Bennett and our own Minister Responsible, Gene Zwozdesky, sit with us for over half a day as we engaged in a dynamic exchange of ideas about how we, as a group of advisors, can further the national disability agenda.

It's a relief to find that we are not alone—every single other province/territory is wrestling with the same issues we are.

The provincial advisors, with our cross-disability mandates, have a significant contribution to make in national dialogue on disability issues. Programs and services for people with disabilities are delivered by provincial governments, and provincial advisors have the most complete knowledge of those services as a whole. As well, there are thousands of provincial and local disability organizations whose voices aren't heard at the federal level since, typically, only large national organizations are consulted regularly (i.e., the Council on Canadians with Disabilities). The bottom line is that federal policy makers need to include



provincial/territorial advisors, which can effectively represent smaller organizations in their own jurisdictions, in order to ensure a more representative consultation.

Dr. Bennett and Mr. Scott also emphasized that disability issues must always be considered within the context of human rights, as set out in the Canadian Charter of Rights and Freedoms and the Universal Declaration of Human Rights. They distributed copies of the recent report of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities, entitled *Reflecting Interdependence: Disability, Parliament, Government and the Community*.

Prior to leaving, Dr. Bennett and Mr. Scott committed the Parliamentary Sub-Committee to holding a two-day disability forum in late fall to discuss disability issues and the federal agenda. Provincial advisors, national disability organizations, key provincial disability organizations, and provincial representatives involved in the Social Union talks will be invited.

There were several key questions we continued to deal with during the meetings: How do we turn the fire up around disability issues during the Social Union talks (the objective of which is to renew and modernize Canadian social policy)? How do we influence policy while it is being developed? How can we hold national leaders accountable for their decisions and actions? Again, answers weren't easy to arrive at. But all agreed that they will be found faster through a coordinated effort.

It's a relief to find that we are not alone—every single other

province/territory is wrestling with the same issues we are. It's also a relief to find that our counterparts in other provinces are passionate about wanting to make a difference—and that there is growing recognition of the need to work together to have the most impact. This past meeting has contributed to the next steps of influencing the federal agenda. In turn, this can only benefit our efforts provincially.

Status Report

Editors: Elaine Chapelle, Cheryl Koss, Cliff Bridges

Design and Production: Bridges Communications

Canadian Publication Mail Agreement No. 1518941

Status Report is published quarterly by the Premier's Council on the Status of Persons with Disabilities and is intended to provoke discussion of issues concerning persons with disabilities. **This publication is also available on audio cassette by contacting our office at:**

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2001 HALS Gets Green Light

Survey success hinges on public commitment

HAL: *I'm sorry, Dave, I don't have enough information.*

Dave: *Open the pod door, Hal.*

In 2001: *A Space Odyssey*, the 1968 masterpiece from Stanley Kubrick and Arthur C. Clarke, crew members of the mission are daunted by HAL, the "heuristically-programmed algorithmic computer." In spite of the information presented to him, HAL is unable to carry out the functions for which he is programmed, therefore compromising the performance of those who rely upon him.

As we actually reach the year 2001, we will find ourselves facing our own HALS, complete with some of the same daunting difficulties of this science-fiction character of similar namesake.

The HALS I speak of is the Health and Activity Limitation Survey, a supplemental questionnaire to the National Census that was initiated in 1986 to provide vital statistics specific to Canadians with disabilities. Replicated in 1991, the HALS data remains the most up-to-date, specific statistical information on persons with disabilities in Canada. Community organizations, programs and government departments still rely on this information for indicators regarding funding, program usage and needs-assessments. While budget restraints prevented the completion of this survey in 1996, Statistics Canada has recently indicated that it has received the necessary support required to add the HALS questionnaire to the 2001 National Census.

Fortunately, our HALS is a valuable representation of persons with disabilities and not a destructive talking computer. Like the fictional HAL, however, our HALS also requires accurate input of information. Without this, HALS data can be potentially misleading and inaccurate. For this reason, the Premier's Council is working closely with other provincial disability advisors across Canada to provide Statistics Canada and Human Resources Development Canada with suggestions on how the HALS 2001 can best be revised so that the most accurate and relevant information will be collected.

HALS also needs a commitment from Canadian citizens. Such a questionnaire, which requires sensitivity and trust from both the interviewer and interviewee, is only as good as the responses collected. In talking with census takers of both the 1991 and 1996 Census questionnaires, we have been told that many families refuse to answer any questions regarding disabilities—for themselves or on behalf of family members who may have a disability. This fact is underscored by results of the 1996 Census in which, while the HALS questionnaire was not used, two questions asked individuals to identify whether or not they considered themselves to have a long-term disability. The definition of a disability was not given, nor were any parameters designated, leaving the response entirely up to the interpretation of the respondent. In Alberta, only 7% indicated having a disability. Compare that to the 1991 HALS data which indicated a provincial result of 17%. Clearly, we know that the number of persons with disabilities has not decreased by 241,000. More likely is that the responses—or lack of—tend to indicate the reluctance to provide sensitive information on personal issues.

Providing information to a total stranger on a subject still associated with prejudice and stigma is understandably difficult for some. However, given the extremely valuable implications that these statistics have for budgets, programs and services, and keeping in mind the absolute confidentiality of information gathered, it is imperative that we make the most of this upcoming opportunity in 2001. Unlike HAL from Kubrick and Clarke's "Odyssey", the Health and Activity Limitation Survey can be turned off quite easily. Considering the reluctance of Statistics Canada to make it a part of the last census, it could be the last opportunity to obtain this data for another ten years.

For more information about the HALS consultations, please contact Renée Langlois, HALS Manager with Statistics Canada, at 613/951-0878 or toll free at 800/263-1136.



Bryan Sandilands

Strategic Directions

In late 1998, the Premier's Council began a strategic planning process. The goal was to create a blueprint to guide the Council during its extended five year mandate.

At a two-day meeting in late April, Council Members, with assistance of facilitators, developed a working draft of a strategic plan. It contains a revised vision and mission statement, a statement of business focus, and priorities requiring action and desired outcomes.

While only a working draft, this plan is a serious statement of direction and is already being used to guide the Council's activities.

Our goal is to gain feedback from organizations of and for Albertans with disabilities, program managers, politicians, and individual Albertans. We have widely circulated the draft and hope to have secured feedback by the end of August. If you have not yet received one, please contact our office at 780/422-1095 or toll-free 800/272-8841, or see our website (www.premierscouncil.ab.ca).

Open House Events

In conjunction with the development of its *Strategic Directions* document, the Premier's Council is planning the first series of annual Open House events throughout the province this fall. The objectives are to:

- provide communities with the opportunity to express "real impact" issues and concerns unique to their experiences.
- provide council with the insight into answering the question: Where do we go from here?
- develop of a provincial disability strategy responsive to input received from each community.
- provide a platform for council members to network and have a reciprocal exchange with each community.
- provide a conduit for the Premier's Council to effectively communicate its new Strategic Directions document.

Specific information regarding date, time and location of this years events has yet to be finalized. Details will be sent to all organizations in our database. For more information, please contact Tom Fowler, Manager of Community Relations and Policy Analysis at 780/422-1095 or 1-800/272-8841.

Edmonton Architect Wins Mayor's Award

Edmonton architect Ron Wickman has received yet another accolade for his work in barrier free housing design.

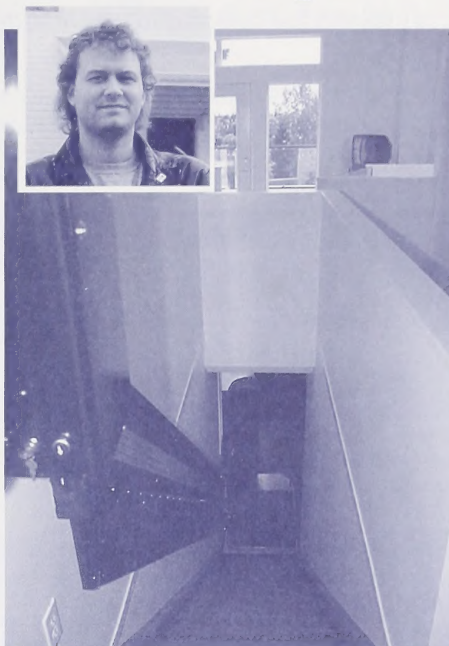
On June 9th, Wickman received the City of Edmonton Mayor's Award for Accessible Architecture (Residential Category) for his work on the Bill Zapf residence. Wickman had been hired by Mr. Zapf, a quadriplegic, to redesign his home on Ada Boulevard in East Edmonton.

The renovations in the house were ambitious and included the addition of a second floor, containing an open multipurpose room with a large balcony providing a breathtaking view of the river valley. Other modifications included redevelopment of the main floor area into an open design, addition of a stair lift, and construction of front and back porches, a mud room, a steam room and, of course, a large bathroom with wheel-in shower. These and other minor modifi-

cations provide Mr. Zapf with more independence.

Wickman, who is a previous winner in the CMHC FlexHousing Competition, says that he will continue to focus on barrier free housing—he forecasts a growing need due in large part to a population that is aging. He can be reached at 780/430-9935.

In the category of Public Service Buildings For All, the judges chose the Lessard Library. Opened in 1996, it is one of the most accessible libraries in Edmonton. There was a great deal of planning done to ensure that the retrofitted mall space could accommodate the library and its potential users. The Lessard design team used the *Accessible Canadian 11* booklet which is a



Wickman's winning design of the Zapf residence included installment of this stair lift to a spacious second floor.

resource tool for libraries serving persons with disabilities.

In the final category, Public

Service Buildings For A Targeted Population, the judges were most impressed with The Good Samaritan Millwoods Care Centre. This centre houses high level, long term care residents with both cognitive and physical disabilities. Each resident has a self contained studio apartment complete with a private bathing area and kitchenette.

The Mayor's Award for Accessible Architecture was established in 1997. It recognizes exemplary project teams (architect, urban planner, builder, designer and/or developer) whose designs or projects demonstrate creative sensitivity for the practical concerns of making urban architecture and community developments accessible to persons with disabilities.

Accessible Condo Phase Two Complete

Phase Two of Creek Side Condominium Project in the Mill Creek area of Edmonton is now complete.

As in Phase One, the second phase has a number of adapted units. Modifications such as large open kitchens, wheel-in showers, accessible balconies, elevators, power doors and reachable wall switches have been incorporated into the building. The features are designed to meet specific needs and provide the purchaser with greater independence.

An innovative feature of this project is the home care program which is managed by the residents. The services are available at no cost on a 24-hour basis to the people living

in the building. By managing their own service, residents are assured of high quality and responsiveness.

Phase Three at Creek Side is now pre-selling. If you are interested in learning more about this great project, call Mike Doris of Barrier Free Innovations Ltd. at 780/433-1923.



Bionics Now Reality

The Princess Margaret Rose Orthopaedic Hospital in Edinburgh, Scotland, claims to have produced the world's most sophisticated bionic arm. Edinburgh modular arm system (EMAS) has motorized shoulder, wrist and elbow joints, as well as contracting fingers, which are all controlled by thought process, thanks to pressure sensors and an advanced microchip. The arm's lifelike covering has wrinkles and fingerprints. The arm, which weighs only four pounds, is being field-tested by Campbell Aird, a 47-year-old hotel worker. It will allow Aird to carry out complex tasks, such as tying shoelaces, for the first time in 16 years.

EnableLink Makes Debut

New website hailed as one-stop disability resource

It's being advertised as "Canada's most comprehensive online resource for people with disabilities."

It's called EnableLink, and it's been designed as a way to link people with disabilities to thousands of online and offline resources, as well as to people and experts within the disability community.

EnableLink (<http://www.enablelink.org>) was developed by the Canadian Abilities Foundation (CAF), publishers of *Abilities* magazine. "EnableLink is the most information-rich online resource yet for people with disabilities," says Raymond Cohen, CAF President. "EnableLink will provide a bridge linking people with disabilities to each other—as well as to the people and resources they need. EnableLink will prove to be particularly beneficial to people new to disability, whether as a result of workplace injury, accident, or a progressive disease."

The website includes a resources section with

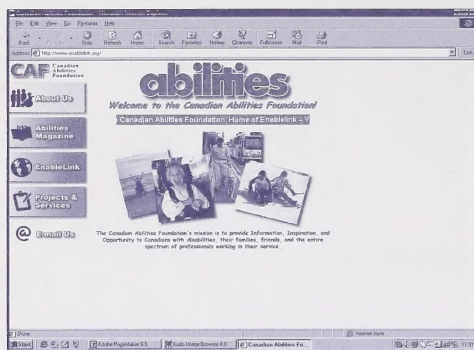
online directories of provincial, national and international disability organizations totaling more than 5,000 products and services, a communication centre which allows users to chat with other online

users, a news and events section listing upcoming disability events and conferences, and a library section and reading room which give users access to a variety of publications.

Cohen stresses that, despite its comprehensiveness, EnableLink is in its infancy. "This marks an important starting point. We expect this website to take hold within the disability community and to

grow, as people begin to explore it, use it and add their input to it. It really is a work in progress."

EnableLink has been made possible with donations from a multitude of sponsors, the most significant being from the Workers' Compensation Boards of Canada. Cohen adds that CAF will continue to seek new sponsors to allow EnableLink to continue its growth.



The EnableLink website features an online directory of more than 5,000 disability organizations—and much more.

Auto Speech Recognition Harmful?

Automatic speech recognition (ASR) software is becoming very popular as a computer-input alternative—particularly for people with disabilities. With ASR programs, you can watch while the words that you speak into a microphone are converted into text on your screen.

But apparently, ASR is not without shortcomings. Voice problems associated with its frequent use have been reported in the mainstream press—vocal fatigue, pain in and around the voice box (larynx), and hoarse voices.

Researchers working at the U of A believe that people with spinal cord injury—particularly quadriplegics—may be at increased risk due to the constraints imposed upon their respiratory and speech systems by their injury. The researchers are conducting a study that's focusing on whether or not people with SCI are using vocal and breathing behaviours with ASR technology that will put them at an increased risk.

If you're a quadriplegic who is interested in furthering research in this area, you can participate in the project by allowing the researchers to record your speech and breathing information while using ASR. Participation involves three separate sessions.

All subjects will be reimbursed for their time and transportation costs. For more information or to find out if you qualify as a candidate, contact Jana Rieger by phone (780/492-7588) or email (jms5@ualberta.ca).



Rebif Rebuffed: MS Drug Doesn't Slow Disease

Results of a three-year, controlled clinical trial of interferon beta-1a (Rebif) for secondary-progressive MS indicate that neither of two different test doses delayed the progression of disability. The trial, conducted by Ares-Serono of Geneva, Switzerland, involved 618 people and took place at 22 clinical centres in Europe, Australia and Canada.

People with secondary-progressive MS begin with a relapsing-remitting course, then develop a progressive course, possibly with relapses and/or minor recovery. While some patients may have benefited, the drug failed to meet the primary goal of the study: to slow the course of the disease.

The drug (or placebo) was self-injected under the skin three times a week for three years. Results of the trial were announced at the annual meeting of the European Neurological Society in Milan, Italy on June 7.

In previous studies of relapsing-remitting MS, Rebif was shown to reduce relapse rate, slow progression and reduce brain lesions detected by MRI. The Ares-Serono group suggested that the disappointing results of the new study could be due to the trial's secondary-progressive patient population having relatively high levels of disability to begin with.

Hope for another drug, however, remains high. According to the National MS Society (USA), positive findings on slowing progression of disability for secondary-progressive MS have been reported from European studies of interferon beta-1b (Betaseron). A study of Betaseron for secondary-progressive disease is underway in North America.

—Source: National Multiple Sclerosis Society (USA)

Definition of Disability Restricted in U.S.

Critics argue that Supreme Court's decision is a "profound setback" to the ADA

From time to time, it's useful for us in Canada to watch disability-related policy developments in the United States.

There, the Americans with Disabilities Act (ADA), since inception nine years ago, has provided broad protection from discrimination to people with disabilities. But the Supreme Court recently released a ruling that narrowed the definition of disability and arguably reduced the ability of the Americans with Disabilities Act (ADA) to protect disabled people from employment discrimination.

By a 7-2 vote, the court ruled in three cases that the determination whether an individual was disabled under the ADA should take into account measures that can correct the impairment.

The ruling was a defeat for two nearsighted pilots, a mechanic with high blood pressure and a truck driver with poor eyesight.

In one case, twins Karen Sutton and Kimberly Hinton

applied to work as pilots for United Air Lines. They argued that their extreme nearsightedness should be considered a disability. They sued after they did not get hired.

In another case, Vaughn Murphy, who has high blood pressure, was hired as a mechanic for United Parcel Service in 1994. Murphy's doctor said he was unable to use medicine to lower his blood pressure below the level required by the federal government without suffering severe side effects. Murphy sued after he was fired.

The third case involved truck driver Hallie Kirkingburg, who has peripheral vision and depth perception, but could not meet the government's vision requirement and sued after he was fired.

All four were deemed non-disabled by the Supreme Court.

The ADA's definition of disability is "a physical or mental impairment that substantially limits" at least one life activity.

In turn, a disabled person is defined as one who is "regarded as having such impairment."

"...the Supreme Court has shown that its understanding of what the ADA intended is far from the understanding of those who drafted the statute."

Justice Sandra Day O'Connor, writing for the majority, said, "We hold that the determination of whether an individual is disabled should be made with reference to measures that mitigate the individual's impairment, including...eyeglasses and contact lenses."

Justice John Paul Stevens, one of two members of the court

who authored a dissenting opinion, said that to be true to the law's purpose it should be given "a generous rather than a miserly construction."

Some disability activists decried the ruling as a "profound setback" to the ADA.

"In ruling against the plaintiffs in the three cases, the Supreme Court has shown that its understanding of what the ADA intended is far from the understanding of those who drafted the statute," said the Center for an Accessible Society in a news release.

Not everyone agrees. "The ruling, in total, amounts to a grand slam for the disabled," wrote John M. Williams in his regular column on assistive technology issues in Business Week Online. "Not only did the court provide more power to individuals to minister to themselves, the justices gave employers a clear definition of what constitutes a disability in the workplace. That's a great victory for disabled workers, for as most people in the corporate world will tell you, the worst enemy of sound business practices is uncertainty."

Meanwhile, a recently completed Lou Harris survey concluded that the ADA is strongly supported by the American public. According to the survey, commissioned by the National Organization on Disability, two thirds of adult Americans are aware of the Act's existence. Of those, 87 percent express approval for it.

Additionally, 75 percent of those surveyed think the benefits of the ADA to people with disabilities are worth additional costs, and 83 percent believe they will lower welfare rolls and create employment opportunities.

Protection for Animal Owners Clarified

In the last issue of *Status Report*, we told you about new assistive animal legislation being developed in British Columbia. In the article, we made this statement: "There is no law in Alberta regarding discrimination against people with disabilities who use assistive animals."

According to Andrew Turzansky of the Alberta Human Rights Commission, the Blind Persons Rights Act does cover discrimination issues for people who use guide dogs. Additionally, says Turzansky, any person with a disability who feels that they have been discriminated against can file a complaint with the Commission.

However, Turzansky concedes that these routes of recourse have considerable shortcomings, the most notable being that only blind people are currently offered specific protection under the current Act. He says that there is a clear need for broad, enforceable legislation that recognizes the rights of all people with disabilities who may use an assistive animal for purposes beyond "guiding"—for example, a wheelchair user who uses a service dog.

Turzansky adds that the Commission is well aware of these shortcomings and is looking at the feasibility of working with appropriate government departments with the goal of creating new or amended legislation that would better protect the rights of all people with disabilities who use assistive animals.

The Blind Persons Rights Act offers specific protection to guide dog owners.



Ferry Code of Practice

New standards for Canadian ferries

The Canadian Transportation Agency (CTA) has just launched a new Code of Practice on Ferry Accessibility.

The Code of Practice, designed to increase the mobility of passengers with disabilities, applies to ferries of 1,000 gross tonnes or more which transport passengers and vehicles between provinces or between Canada and the United States.

The Code ensures equipment accessibility and offers practical and functional solutions to systemic accessibility problems encountered by persons with disabilities and seniors. For example, an operator should ensure that a wheelchair user can freely access an elevator.

The essence of the accessibility

criteria of the Code is as follows: All ferries of 1,000 gross tonnes or more should satisfy by January 1, 2002, accessibility criteria for signage, communication of information, supplemental passenger briefing cards, lighting, stairways, handrails, corridors and passageways, floors, doorways and doors, counters, telephones, alarms, elevators, vehicle decks, passenger lounges, cafeterias, cabins, and washrooms.

Keep in mind that the Code, developed in cooperation with industry representatives and consumers, is voluntary in nature. In other words, ferry operators aren't bound to follow its recommendations. The CTA indicates it will conduct periodic surveys to monitor implementation process and will deal with individual complaints to determine whether there is an undue obstacle to the mobility of persons with disabilities.

The Code of Practice is available on the Internet (www.cta-otc.gc.ca).



Rental Van Program Grows

The Canadian Paraplegic Association (Alberta) and Rent-a-Wreck are proud to announce the second addition to the wheelchair accessible rental van program. With the addition, there is now a van available in each of the Edmonton and Calgary areas.

The new van is a 1987 Chevy, equipped with a lowered floor, Vangator platform lift and manual tie down system. It has room to accommodate one person seated in a wheelchair, three passengers on the bench seat across the back, and the driver. There's also plenty of storage room.

A lease agreement has been established between Rent-a-Wreck in Northeast Calgary and CPA Alberta. Revenue from the rental of the van goes to cover operating and maintenance expenses. Any surplus is returned to CPA in hopes of purchasing a newer rental van. Rental prices begin at \$44.95 per day.

If you would like to rent the new van or more information, contact Tom French at Rent-a-Wreck, 1210 Meridian Road NE, Calgary, phone (403) 273-5800.

Alberta Infrastructure Update

Alberta Transportation and Utilities is now part of the new department called Alberta Infrastructure. The department has retained its commitment to accessible transportation and pedestrian environments for people with disabilities.

This summer, Alberta Infrastructure is installing the wheelchair accessibility symbol on Gasoline Alley signs (along the Red Deer corridor of Highway 2) for qualifying businesses. The signs will clearly indicate to travellers with disabilities which businesses are accessible.

As a further aid to the motoring public, roadside call boxes will be installed along Highway 2 by AlbertaMAS (Motorist Aid System). The call boxes will be located at 16 kilometre intervals on alternating sides of the divided highway. Each call box "pad" is fully accessible to users of mobility devices, and amplification is provided for users who are hard of hearing. Fifteen call boxes have already been installed and are operating on Highway 1 between Banff and Calgary.

AlbertaMAS has an agreement with Alberta Infrastructure to install approximately 400 wireless solar powered call boxes along primary highways during the next two years.

Meanwhile, in the Alberta capital, Edmonton Transit System is increasing the number of cars with accessibility ramps on its Light Rail Transit (LRT) line. The new ramp-equipped vehicles will help alleviate scheduling problems that resulted with only one ramp-equipped car in operation. By the end of 2001, all LRT cars will have an access ramp.

Ski Year Round!

The Alberta Association of Disabled Skiers wants you to know that you can take advantage of its programs all year long. The Association operates three separate programs each year: water skiing, alpine, and cross-country.

The Association is able to offer individualized instruction to students with disabilities. Specialized equipment ensures a fun and safe experience for every participant. For the more advanced skiers, a learn-to-race program offers added challenges. In the sit ski program, both mono and bi-skis are available.

The Edmonton water skiing program, which started on June 14, takes place at Wizard Lake just west of the city. Weather permitting, the schedule called for skiing, swimming and barbecues for eight Monday evenings. For more details on the summer program, call 780/439-4499.

During the winter, there will be alpine skiing at Rabbit Hill on eight Wednesday nights and cross-country skiing at Victoria Golf Course on six Tuesdays.

Registration fees are kept as low as possible. Transportation isn't provided, but members do carpool. Students and volunteers of all ages and abilities are welcome.

For more details on the programs in your area, call the provincial office at 780/427-8104.

Taking Aim at Couch Potatoes

New program promotes active living for people with disabilities

Pfizer Canada Inc., the pharmaceutical giant best known for its recent debuting of Viagra, has teamed up with the federal government to support a new campaign aimed at reducing inactivity in Canadians with disabilities.

"Viabilité", an ambitious five year program, aims to increase the physical activity of Canadians with a disability. The initiative, which was launched in June by the Active Living Alliance for Canadians with a Disability (ALACD), received \$500,000 in seed funding from Health Canada and another \$200,000 over four years from Pfizer Canada Inc.

"This is a great example of how we can work together," said Health Minister Allan Rock, who was present for the unveiling of the program. "With partnerships among the public, corporate and non-profit sectors, we can make things happen."

The funds from Health Canada and Pfizer Canada Inc. will be used to support the most ambitious and concerted effort ever to encourage Canadians with disabilities to lead more active lives and reap the health benefits. The initiative is being spearheaded by ALACD, a non-profit, non-governmental organization. It is in direct response to the collective goal set in August 1997 by the federal and provincial/territorial Ministers responsible for fitness. This goal called for a 10% decrease in the number of inactive Canadians by the year 2003. Health Canada estimated the related health care cost savings at approximately \$5 billion. ALACD aims to exceed that goal and has pledged to reduce the



inactivity of Canadians with a disability by 20% by 2003.

Theresa Firestone, Vice President, Government and Public Affairs at Pfizer Canada Inc., spoke about the company's continuing commitment to "Viabilité," by pledging to assist with the recruitment of additional corporate partners to the program.

"We're proud to offer our support to the Active Living Alliance with this important initiative and help them reach their goal," said Firestone. "By increasing the physical activity and improving the health of people with disabilities, health care costs will be significantly reduced and the quality of lives improved."

ALACD's five-year social marketing initiative will enable Canadians with disabilities to reap the benefits of an active lifestyle. "There are 4.2 million people living with a disability in this country—that's 15.4% of Canadians," stated Linda Hancock, Chair of ALACD.

"We not only want to promote the benefits of an active lifestyle, but also to deliver our message to others such as health care pro-

fessionals, suppliers and owners/operators of sport and fitness facilities."

Eric Boyd, Past Chair of ALACD, and Chantal Benoit, a member of the Canadian Women's Wheelchair Basketball Team for the past 14 years, also attended the launch and discussed the positive effects that active living has had on their lives and announced their support of the "Viabilité" program.

"The whole initiative has profound implications for the enhancement of lifestyles of people with a disability," said Boyd. "Viabilité will play a catalytic role in reducing health care costs by over a billion dollars by 2003."

Chantal Benoit, two-time Paralympic Gold Medalist and two-time World Champion in Wheelchair Basketball, had a simple but straightforward message for those assembled for the launch: "Be in love with what you do and share that with members in your community."

ALACD is a partnership of 15 national organizations with an interest in active living and disability. Its mission is to promote inclusion and active living lifestyles of Canadians with disabilities by facilitating communication and collaboration among organizations, agencies and individuals. Together, members of the Alliance are working toward a vision of full and equitable access to active living opportunities for persons with a disability.

For more information, contact Reg McClellan, Viabilité Manager, by phone (800/771-0663) or e-mail (reg@fws.ca), or check out the website (www.viabilite.com).

DaimlerChrysler Corp Seeks Used Wheels

What happens to a wheelchair once a person has outgrown it? Often, it sits in the garage unused.

DaimlerChrysler Corporation and Wheels for the World, a non-profit organization that provides wheelchairs for people around the world, are trying to change that by collecting and transporting pre-owned wheelchairs to countries where wheelchairs can be used again—giving new owners a chance at mobility.

In April, Wheels for the World carried out a two-weekend drive to collect wheelchairs in the metro Detroit area. DaimlerChrysler's transportation department provided a semi-truck trailer and driver to deliver the wheelchairs to Nashville, Tennessee, for refurbishing. After that, the wheelchairs will be delivered to Romania, Poland and Ghana—places where an old wheelchair can grant a fresh and mobile view of the world.

"As a transportation company, DaimlerChrysler realizes the importance of mobility and the freedom to move as one pleases," said Bill Lamott, DaimlerChrysler Transportation Manager. "Working along with Wheels for the World has given DaimlerChrysler the opportunity to help those in need of the mobility a wheelchair can provide, which is often the only form of transportation available."

"This drive is an amazing answer to many prayers," said Dorothy Pitsch, metro Detroit chairwoman. "We expect to obtain several wheelchairs, but transporting them is a big part of the process. DaimlerChrysler has stepped to the plate and agreed to help our mission. The word is spreading and everyone wants to help."

This is the first multi-city drive. The average large-city drive collects about 200 chairs, said Pitsch.

Wheels for the World has placed 6,000 people in wheelchairs since its inception in 1992. Wheels for the World was founded by Joni Eareckson Tada, who became a quadriplegic in a diving accident.

Financial Planning for Caregivers

Program offers seminars to community organizations

Should financial planning and estate planning be a top priority for parents who take care of dependent children?

Absolutely, says Wayne Taylor of the Edmonton-based Taylor Financial Group. "The health care system is being stretched and the medical care and support people take for granted is not guaranteed for the future," says Taylor. "The rewards of taking care of family are very real and create wonderful lifetime memories. The demands are also very real—these parents often become physically exhausted and drained emotionally and spiritually by the daily caregiver demands placed on them. They can become so stressed it robs them of the necessary energy to do proper planning for the future."

Taylor has joined forces with fellow financial planner John Willms and a number of other qualified individuals to create Family Finance & Estate Planning Associates. Taylor says the organization's



goal is to help caregivers ensure they have their financial and legal affairs in order—a process which may include the use of insurance, financial planning, wills, enduring power of attorney and personal care directives.

"Peace of mind results with knowledge that these planning issues have been addressed in anticipation of current and future needs," says Taylor. "Advanced

planning removes some stress from the caregiver's life that allows them more energy to meet the challenges of caring for their other family needs. By having this planning done, the risk of the 'tax department' being a significant beneficiary can be reduced."

The Family Financial & Estate Planning Associates are available to groups interested in organizing a 45 minute information seminar. You can contact the group c/o John Willms or Wayne Taylor at 780/451-3152.

John Ryan's Regeneration Tour Coming to Alberta

John Ryan's four month cross-country journey on a handcycle is well over the halfway mark by the time you read this issue of *Status Report*.

Ryan, a T12 paraplegic from Whistler, B.C., is hoping to raise \$5 million for spinal cord regeneration research.

At press time, Ryan had just entered Manitoba, two months after starting his journey in St. John's, Newfoundland. He's scheduled to enter Alberta on August 12 along the Trans Canada Highway. His first leg into Alberta will take him to Irvine; he'll take about a week to make his way through Calgary and to the B.C. border.

At right is the tour's itinerary for Alberta. For more information, see the tour's website (www.regenerationtour.org) or call 800/570-3222.

Regeneration Tour Alberta Itinerary

Thursday, August 12 (Day 104): Ride from Sidewood, SK to Irvine, AB
 Friday, August 13 (Day 105): Ride from Irvine, AB to Anderson, AB
 Saturday, August 14 (Day 106): Rest
 Sunday, August 15 (Day 107): Ride from Anderson, AB to Bassano, AB
 Monday, August 16 (Day 108): Ride from Bassano, AB to Strathmore, AB
 Tuesday, August 17 (Day 109): Ride from Strathmore, AB to Calgary, AB
 Wednesday, August 18 (Day 110): Rest
 Thursday, August 19 (Day 111): Ride from Calgary, AB to Canmore, AB
 Friday, August 20 (Day 112): Ride from Canmore, AB to Alberta-BC Border



MetLife Introduces Services for Special Needs Families

MetLife, a leading American provider of insurance and financial services, recently introduced a new marketing division that will focus on the financial concerns of families with special needs children.

MetDESK (DESK is short for Division of Estate Planning for Special Kids) offers a staff of specialists and a website where visitors can learn about financial issues for special needs children.

While only available in the U.S., the service—particularly the website—may still be a good source of information for Canadian parents.

The MetDESK website provides detailed information on products and services available and a list of links to related sites such as The National Institute on Disability and Rehabilitation and *Exceptional Parent* magazine.

According to a news release from the company's public relations division, MetDESK specialists are trained to take clients through a comprehensive planning process designed to help address the financial, legal and governmental issues related to their special needs children.

The specialists work closely with special needs attorneys and can help families develop plans to provide funds, meet various long-term care needs, and preserve benefits from government agencies.

For more information, pay a visit to the website (www.metlife.com/desk).

An Ethical Cry for Injury Control

The annual health care burden of injury on our society exceeds that of cancer, yet the resources allocated to injury control research pale in comparison to those allotted to cancer research. Why?

I see the problem being one of the treatment arm of health care being pitted against the preventative arm in a battle for the limited resources available. Despite recent talk of creating a more preventative, wellbeing-based health care system, it appears the treatment perspective is winning. I believe all Albertans will lose if injury control isn't addressed as a top priority.

The injury problem needs the same commitment to funding for research that has been made to AIDS, breast cancer, and heart and stroke disorders.

Effective injury control is based on injury surveillance, data analysis, and program evaluation. Injury control encompasses development of effective prevention approaches, improving pre-hospital and trauma care, and aggressively rehabilitating those recovering from injury.

I believe that, of these three areas, we have failed most in the area of prevention.

You may better know injuries as "accidents" or "freak accidents". These terms are misnomers—they imply nothing can be done to prevent them. But injuries are predictable and preventable.

Injuries should be simply cat-

egorized as either intentional or unintentional. Intentional injuries can be either self-directed, such as suicide, or directed at others, such as assault. Unintentional injuries include motor vehicle collisions and falls.

Whatever the cause, it's important to again stress that injuries are both predictable and preventable. Injuries can be best prevented by many approaches. The most successful strategy is through engineering changes such as better vehicle and road design, and the design of safer products and environments. This approach does not require the individual to make a conscious safety choice. An enforcement approach through legislation, though not popular at times, is another effective means—take seatbelt legislation as an example. Economic incentives, such as discounted insurance premiums for having smoke detectors installed, is another emerging approach. Finally, education campaigns, though not very successful in the past, remain a method for trying to reduce incidence of injury.

The most successful of strategies involve a combination of these approaches.

When correctly researched and implemented, injury prevention strategies work. In spite of knowing this, it is clear we have not taken enough strides in this direction. Injuries are the leading cause of death for Canadians under the age of 44. Motor vehicle-related injuries are the leading cause of death for those under the age of 34. And injuries kill more children over the age of one than all other childhood diseases combined.

Although it should be obvious, it appears necessary to ask, "Why should we pay attention to injury prevention and control?

What ethical imperative would require us to do so at the expense of attention to other diseases?"

Presumably, the reason that we as a society devote the resources we do to health care is that we wish to advance the wellbeing of our community. That we offer these services on the basis of need implies that we believe all members of our community have an equal opportunity to be free of the burdens of disease and disability.

If this is the case, then it makes sense from an efficiency perspective to attend to those factors that are known to most compromise health care. And again, it is clear that injuries, intentional and unintentional, are a major, if not the most important, cause of compromise to individual health and wellbeing. The injury problem needs the same commitment to funding for research that has been made to AIDS, breast cancer, and heart and stroke disorders.

Given the startling statistics mentioned above, one would think that the logic of this ethical argument would prevail and we, as a society, would be outraged and demand something be done. But that hasn't happened. Why?

Every other disease known to man has an organization that raises concern about that disease. We know who they are and what they do—and they do it well. In contrast, when was the last time someone knocked on your door and asked for a donation so that more research could be done for injury control? Why is this? There are many theories:

- Decision and policy makers aren't threatened as much by injuries as they are by heart disease and cancer.
- Many of those affected by injuries are socially stigmatized

members of society.

- A misperception exists that injuries are random events and unavoidable; we have become desensitized by media reports of how commonplace these events are.
- Past attempts made by well-meaning individuals with no training in the field have had limited results.

Whatever the reasons, Alberta has failed to meet the challenge of injury control through provision of adequate resources. The Provincial Health Council, in its June 1998 report, identified injuries as an area that needed immediate attention. The province has responded with a positive small first step with the creation of the Alberta Centre for Injury Control and Research. If properly funded and mandated, the Centre can make a difference. But one does not tackle a multibillion-dollar problem with limited resources and expect measurable outcomes.

The ethical cry for injury control makes sense. We can and should spend our health care dollars more efficiently by addressing predictable and preventable injuries.

This guest editorial is condensed from In Touch, published by the Provincial Health Ethics Network, February 1999.

Dr. Francescutti founded the Injury Prevention Centre at the University of Alberta Hospitals and developed the award-winning multimedia injury prevention program for teenagers called HEROES. He is currently Chair, Advisory Body, Alberta Centre for Injury Control and Research. He is an Assistant Professor at the Department of Public Health Sciences at the University of Alberta, and also works as an emergency physician at the Royal Alexandra Hospital.

EMPLOYMENT

Performers Unions Debut Disability Resource Card

Three performers' unions—Actors Equity, American Federation of Television and Radio Artists (AFTRA) and Screen Actors Guild (SAG)—have introduced a special Industry Resource Card designed to educate the entertainment industry about working with performers with disabilities.

The card was debuted by Screen Actors Guild President Richard Masur at a press conference on April 27 in New York.

"Everything You Always Wanted to Know About Working with Performers with Disabilities But Were Afraid to Ask" is a two-sided, laminated card being distributed to production companies, talent agents, casting offices and other industry related groups. The card provides answers to questions, key contact numbers for helping arrange accommodations that may be needed and, hopefully, more understanding of the fact that disabled actors can and do work.

"Our goal is to acknowledge the many disabled performers working in movies, television, theatre, commercials and industrials," explained Masur, who has been outspoken about this issue for quite some time. "These actors are not limited by their wheelchairs, hearing disabilities, guide dogs, interpreters or by the set's cables, scenery, cameras or stages. They are only limited by other people who think these talented professionals can't do the job."

"We hope these materials will address many of the more common questions that are asked, and provide sources that can offer answers and assistance," said AFTRA National President Shelby Scott.



"Despite significant gains made in the areas of non-traditional casting, actors with disabilities still remain vastly under-represented on our stages as well as on film and television," said Ron Silver, President of Actors' Equity. "Hopefully this resource will serve to counter this inequity by reminding creative decision makers that the presence of a physical disability neither negates nor dissipates an actor's talent."

Actors' Equity Association is the 40,000 member union of professional actors and stage managers in the legitimate theatre. Members work on Broadway, in regional theatres, dinner theatres, summer stock, theatres for young audiences, Disney World and at Small Professional Theatres throughout the country.

The American Federation of Television and Radio Artists represents approximately 80,000 actors, news broadcasters, talk show hosts, announcers, singers, dancers and others who work in the fields of television, radio, sound recordings, commercials and non-broadcast/industrial productions.

The Screen Actors Guild is a national union representing over 96,000 principal and background actors, singers, dancers, stunt performers, voice-over artists, pilots, puppeteers and models working in everything from television and film to interactive multimedia productions.

calendar

Aug 16 - 18, 1999

The Calgary Learning Centre presents its Summer Institute 1999. Location: University of Calgary's MacEwan Student Centre. Theme: A World of Difference—Issues and Practice in the Assessment of Multicultural Learners. Contact the Calgary Learning Centre at 403/686-9300.

Sept 16 - 19, 1999

The Spina Bifida and Hydrocephalus Association of Canada presents its National Conference. Location: Radisson Hotel in Saskatoon, Saskatchewan. Theme: Bridging the Gap—bringing together families, educators and health care professionals to assist in improving the quality of life of all individuals with spina bifida or hydrocephalus. Contact SBHAC at 800/563-9488.

Sept 27 - 29, 1999

The Canadian Paraplegic Association (Alberta) and the Brain Injury Association of Alberta present Neurotrauma Connections '99: An Alberta Symposium and Assistive Technology Trade Show. Location: Mayfield Inn and Convention Centre in Edmonton. Theme: working together in neurotrauma research, rehabilitation and prevention. For more information, contact the Canadian Paraplegic Association at 424-6312 (Edmonton) or 888/654-5444 (toll-free), or visit the Symposium website (www.connections-99.com).

Sept 30 - Oct 2, 99

The Canadian Institute for Barrier Free Design and the Faculty of Architecture, University of Manitoba, present the first Universal Design conference in Canada. Location: Sheraton Winnipeg. Theme: advancing understanding and knowledge of universal design issues. Contact Susan Shanley, Conference Coordinator, at 204/474-7533.

Oct 5 - 6, 1999

Alberta Children's Services presents the first annual Alberta Children's Forum. Location: Edmonton. Theme: First Circle: Uniting for Children. Contact: Brian Kearns at Alberta Children's Services at 780/415-0085.

Nov 25 - 27, 1999

The Learning Disabilities Association of Alberta (Calgary Chapter) presents the 20th Annual Provincial Conference: LD > 2000. Location: Westin Calgary. Theme: three day conference dealing with a wide variety of subjects relating to learning disabilities experienced by children and adults. Contact: Learning Disabilities Association of Alberta (Calgary Chapter) at 403/283-6606.

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